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End of life care for people with intellectual disability: a retrospective cross sectional UK study

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Abstract

Background: Adults with intellectual disability (ID) experience inequality in access to healthcare that is considered to extend to end of life care. Their experiences of healthcare at end of life and how these compare with the general population are unknown.

Aim: to describe end of life care outcomes for adults with ID living in residential care in the UK using the VOICES-SF questionnaire and compare these with the general population.

Design: Nationwide population-based post-bereavement survey.

Participants: 38 ID care providers took part in the study. They supported over 13,000 people with ID. Over the 18 month period of data collection, 222 deaths were reported. The survey was completed, by care staff, for 157 (70.7%) of those deaths.

Results: Decedents had complex health, functional and behavioural needs. Death was unanticipated in a high proportion of cases. Quality of care provided across care settings was generally well-rated. However, hospital care and care provided at the time of death was less well-rated, particularly in comparison to the general population. Respondents reported low levels of involvement in care and awareness of approaching death among adults with ID, and lower than in the general population.

Conclusion: Access to end of life care for adults with ID may be constrained by a failure to identify approaching end of life. The high proportion of unexpected deaths in this population warrants further study. There is a need to increase and support involvement of adults with ID to be active partners in planning care at the end of their lives.

Background

There are estimated to be 1.3 million people with Intellectual Disabilities (ID) in the UK, about 2% of the population¹. They often have complex health, social and behavioural needs^{2, 3} and can be at particular risk of health inequality, social exclusion, discrimination and premature death⁴⁻⁹. As this population continues to age^{10, 11}, increasing numbers are dying from illnesses that require end of life care^{12, 13}. Although there are concerns that the end of life care needs of adults with ID are not well met^{4, 14-18} or not identified at all¹⁹, the existing literature is often qualitative in nature^{18, 20-22} and unable to offer a population perspective.

In England and Wales representative end of life care data have been collected from bereaved relatives^{23, 24} using the VOICES-SF questionnaire²⁵. However, these surveys provide an incomplete account of end of life care for adults with ID because only a small number are captured by the sampling strategy and serious under-reporting of ID on death certificates underestimates the prevalence of ID^{4, 26}. To address this gap, we conducted the first national population-based survey of end of life care for adults with ID living in ID services. It is likely that almost half of adults with ID, a proportion that increases with age, will live in supported living and residential care settings^{6, 27}. In the Confidential Inquiry⁴ into premature deaths of people with ID, which examined all known deaths of people with ID aged 4 years and older over a 2-year period in 5 Primary Care Trust (PCT) areas of South West England, it was reported that 64% were living in such settings at the time of their death. Such settings are distinct from those for older nondisabled adults and are unlikely to be familiar to many non-ID professionals¹. This paper presents data on end of life care for this population and compares these with those for the general population.

Methods

Objective

To describe experiences and quality of end of life care in the UK for adults with ID from the perspective of the staff who cared for them.

Sampling and recruitment

The calculation for sample size was based on place of death. Using a true proportion of 68% of adults with ID dying in hospital, we calculated that a sample of 182 decedents would be required to provide 80.0% power at $\alpha=0.05$ (2-tailed) to detect a significant difference from the general population proportion of 58%. Using an estimate from exploratory work that 1.13% of this population die over a 1 year period, we aimed to recruit services that provide support to 11,000 adults with ID to capture the sample of 182 decedents over 18 months. Data were sought from 80 providers of residential care for adults with ID across the four countries of the UK (fully described elsewhere²⁸). The participating services provided data on clients who died whilst in their care, regardless of place of death. Data were collected between 1st July 2013 and 31st December 2014: services provided retrospective data every six months.

Measures

For each death identified, participating services provided information on age, gender, place of death and as much detail about the cause of death as they could. In addition, they were asked to identify

a member of staff who knew the decedent well, had been involved in their care in the last months of life, and who could complete the ID sensitive VOICES-SF.

VOICES-Short Form is a 59-item questionnaire about care preferences, experiences and quality of care provided in the last three months of life completed usually, but not exclusively, by a bereaved relative ²⁵. Minor modifications were made to ensure that VOICES-SF was sensitive to ID care settings. For instance, it was made clear that home meant the usual place of residence, and reference was made to nurses for adults with ID and ID-specific support needs.

General population VOICES-SF data

Between 2011 and 2015 representative surveys of end of life care were conducted annually in England and Wales using the VOICES-SF questionnaire. Approximately 49,000 deaths were sampled each year with an average response rate of 45% ²⁴. As data on our ID population were collected between 1st July 2013 and 31st December 2014, we have used the 2014 survey data for comparison.

Analysis

Data were analysed using SPSS for Windows 22. Descriptive and bivariate data analyses were performed. The latter involved comparisons between groups of decedents using Chi Square or Fishers Exact Test. Due to differences in sampling methods and sample size, comparisons between data from this study, and the general population VOICES-SF survey were made descriptively using frequencies and percentages. Missing data were excluded from analysis and identified, where appropriate, on tables.

Results

Eighty service providers were approached, 38 (47.5%) participated and they supported 13,187 adults. 36 providers were able to describe their supported population in more detail. They supported 12,804 adults in 3080 care settings across the UK (England: n=10,463 – 81.6%; Wales: n=1140 – 8.8%, Scotland: n=969 – 7.8%, Northern Ireland: n=232 – 1.9%). Over the 18 month period of data collection, core data were obtained for 222 deaths which met our sample size requirements. A total of 188 questionnaires were sent to staff in the care setting, representing 85% of the deaths identified. It was not possible to send these for 34 deaths since no contact details were provided. Of the questionnaires sent, 158 were completed and returned. However, one questionnaire was largely incomplete. Thus detailed data were obtained for 157 deaths which represents a response rate of 70.7% for the 222 deaths identified.

Demographic characteristics

Table 1: Characteristics of the sample

Characteristic	ID sample (n=157) Frequency (%)	National sample (n= 21,403) Frequency (%)
Age		
18-39	5 (6.4)	-
40-49	25 (15.9)	-
50-59	39 (24.8)	1181 (5.5)*
60-69	46 (29.3)	2251 (10.5)
70-79	25 (15.9)	4236 (19.8)
80-89	14 (8.9)	8184 (38.2)
90+	3 (1.9)	5551 (25.9)
Missing	0	
Gender		
Male	101 (64.7)	9834 (45.9)
Female	55 (35.3)	11569 (54.1)
Missing	1	
Cause of death		
CVD	28 (19.7)	5836 (27.3)
Cancer	22 (15.5)	6703 (31.3)
Other	92 (64.8)	8864 (41.4)
Missing or could not be established	15	
Comorbidities		
Down Syndrome	34 (21.7)	N/A
Autism	17 (10.8)	N/A
Epilepsy	62 (39.5)	N/A
Challenging behaviour	59 (37.6)	N/A
Missing	0	
Place of death		
Home	78 (49.7)	4658 (21.8)
Hospital	78 (49.7)	10018 (46.8)
Care home	1 (0.6)	5328 (24.9)
Hospice	0 (0)	1399 (6.5)
Missing	0	
How long had he been ill before he died?		
He died suddenly	27 (17.3)	1532 (8.2)
Less than 24 hours	5 (3.2)	211 (1.0)
> 1 day, < 1 week	12 (7.7)	1044 (5.0)
> 1 week, < 1 month	25 (16.0)	2005 (9.5)
> 1 month, < 6 month	34 (21.8)	4364 (20.6)
> 6 month, < 1 year	22 (14.1)	2367 (11.2)
> 1 year	31 (19.9)	9202 (44.5)
Missing	1	
Support needs – complete without help:		
Drink a cup of tea	66 (43.1)	N/A
Go from room to room	59 (38.3)	N/A
Use the toilet	36 (21.7)	N/A
Get dressed	17 (11.1)	N/A

Use a bank account missing	3 (2.0) 5	N/A
Care received from		
Community nurse	84 (54.5)	7139 (33.2)**
Registered nurse (Learning disability)	58 (37.7)	N/A
Marie Curie nurse	6 (3.9)	942 (4.2)
Hospice at Home	5 (3.2)	815 (3.7)
Macmillan nurse	28 (18.2)	3485 (16.0)
Any other nurse	7 (4.5)	N/A
Occupational therapist	34 (22.1)	1801 (8.4)
Home care worker	15 (9.7)	5283 (24.0)
Social worker	43 (27.9)	1708 (8.0)
Missing	4	

*ONS data summarised as 18-59 years

**Not collected so figures taken from 2015 data

Care settings had a mean of 5.4 residents (SD=4.9), the mean length of residence was 11.8 years. The mean age at death was 61.6 years, only 17 decedents (10.8%) were aged over 80 years of age (Table 1) and 64.7% of the sample were male (n=101). Thirty four decedents (21.7%) were reported to have had Down syndrome. The same number were reported to have been living with dementia. Of the decedents with DS, 22 (64.7%) had dementia compared to 12 (9.8%) who did not have DS. Of those without DS and aged over 70 years, 9 (22.5%) were reported to have had dementia. Seventeen decedents were reported to have had autism (10.8%) and 62 (39.5%) epilepsy. In addition, 59 (37.6%) were reported to have had 'challenging behaviour'. Support needs for activities of daily living were perceived as high (Table 1). For example, 59 (38.3%) were able to move from room to room without support, 88 (59.4%), with some support, as being able to understand what someone said to them and 78 (51.0%) as able to make someone else understand what they were saying.

Conditions other than cancer and CVD were the predominant reported cause of death (n=92, 64.8%), with 'respiratory illness' being the most common (n=44; 31.0%), excluding aspiration pneumonia (n=14, 9.9%). Thirty-two (20.5%) decedents were reported to have died 'suddenly' or had been ill for 'less than one day' and 53 (34.0%) had been ill for 'six months or more' before death (Table 1). For those that had been ill for 6 months or more, 13 (24.5%) had died from cancer and 17 (32.1%) had dementia. Of the sudden deaths, 14 (43.8%) were deaths from CVD. Death from respiratory illnesses was as common in sudden deaths (n=7, 21.9%) as it was deaths preceded by an illness of more than 6 months (n=10, 18.9%).

Equal numbers died in the care setting in which they had lived as in hospital (n=78, 49.7%) (Table 1). None were reported to have died in a hospice. The relatively high proportion of deaths at home, compared to the general population, was not explained by the high rates of 'sudden' death: 16 (50.0%) 'sudden' deaths occurred at home compared to 61 (49.2%) other deaths ($\chi^2 = 0.01$, df=1, p=0.90). Death at home was more likely for those who had been ill for six months or more (n= 36, 67.9%) than for those who had been ill for a shorter time (n=41, 39.8%) ($\chi^2 = 9.97$, df=1, p=0.01).

Twenty-eight decedents (18.2%) received care from a specialist palliative care nurse and a number of other services were also received (Table 1). The majority of respondents felt that they had received all the support they wanted from external services (n=77, 63.1%). When death occurred at home, respondents were more likely to report sufficient external support (n=45, 78.9%) than when death occurred within hospital (n=32, 59.2%) ($\chi^2 = 5.06$, df=1, p<0.05).

Table 2: Involvement in care planning and care preferences

VOICES questionnaire item	ID sample Frequency (%)	National sample Frequency* (Weighted %)
Did he know he was likely to die?		
Yes, certainly	6 (5.0)	34.0
Yes, probably	20 (16.8)	27.5
Probably not	55 (46.2)	21.5
No definitely	38 (31.9)	17.0
Not sure	37	
missing	1	
Did he ever say where he would like to die?		
Yes	19 (12.4)	34.9
No	119 (77.8)	59.6
Not sure	15 (9.8)	5.5
missing	4	
Where did he say he would like to die?		
At home	19 (100)	6308 (81.5)
In a hospice	0 (0)	657 (8.2)
In a hospital	0 (0)	190 (2.6)
In a care home	0 (0)	539 (6.3)
Somewhere else	0 (0)	104 (1.4)
missing	0	
Did the health care staff have a record of this?		
Yes	15 (83.3)	3834 (41.9)
No	1 (5.6)	1818 (20.8)
Not sure	2 (11.1)	3359 (37.3)
missing	1	
Do you think he had enough choice about where he died?		
Yes	38 (40.9)	51.1
No	18 (19.4)	23.1
Not sure	37 (39.8)	25.7
Not appropriate	53	
missing	11	
On balance do you think he died in the right place?		
Yes	121 (80.7)	81.9
No	17 (11.3)	10.8
Not sure	12 (8.0)	7.3
missing	7	
Looking back over the last three months of his/her life, was he/she involved in decisions about his/her care as much as he/she would have wanted?		
Yes	66 (45.8)	86.3
S/he would've liked to be more involved	3 (2.1)	13.1

[S/he would've liked to be less involved] S/he was not able to be involved Don't Know Missing	[N/A] 75 (49.7) 7 6	[0.6] 26.8
Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted? Yes Would've liked to be more involved Don't know missing	137 (89.0) 12 (7.8) 5 (3.2) 3	76.4 23.4 0.2
Were any decisions made about his/her care that he/she would not have wanted? Yes No Don't know Missing	14 (9.3) 89 (59.3) 47 (31.3) 7	19.2 60.7 20.1

*Frequencies not available for some questionnaire items

Involvement, priorities and preferences

Home was the preferred place of death for all nineteen (12.4%) decedents for whom a preference was reported (Table 2). A record for this preference was present for most of these people (n=15, 83.3%). Of those with a stated preference, the majority died in what was reported to be the preferred place (n=14; 73.7%). The remainder died in hospital (n=5; 26.3%). For the majority of deaths across the whole sample, respondents felt that the person had died in the right place (n=121, 80.7%). This was higher for deaths that happened at home (n=73, 98.6%) than in hospital (n=48, 75.0%) ($\chi^2=16.64$, $p<0.01$). Respondents felt that, for thirty eight (40.9%) of the decedents, there had been enough choice concerning place of death.

The majority were reported to have been 'not aware' or 'probably not aware' that they were dying (n=93, 78.2%), although 23.7% (n=37) of respondents were unsure if the decedent was aware of approaching death or not. As expected, those who were reported to have capacity were statistically significantly more likely to know both that they were going to die (45.0% compared to 18.1%, Fisher's exact $p<0.05$) and say where they would like to die than those who were reported not to have capacity (44.0% compared to 7.48%; Fisher's exact test $p<0.01$).

Only 14 (9.3%) respondents reported that decisions were made that the decedent would not have wanted, although many reported that they did not know (n=47, 31.4%).

Quality of care

Overall, ratings of perceived quality of care were positive (Table 3). For instance, 92.2% of respondents (n=83) identified that the care provided by community nurses was 'excellent' or 'good' and 91.6% reported (n=108) that GP care was 'excellent' or 'good'. Ratings for hospital staff were less positive but still high (Table 3). Care by community nurses was more often rated to be 'excellent' or 'good' than care delivered by hospital nurses ($\chi^2=9.89$, $df=1$, $p<0.01$) and the same was found between GPs and hospital doctors ($\chi^2=13.72$, $df=1$, $p<0.01$). 122 care workers reporting on anticipated deaths (deaths they did not deem to be 'sudden') were asked if they received sufficient support from external health and social care professionals in the last three months of the individual's life. Of those, 77 (63.1%) said the level of external support was sufficient. The level of support at the time of death was reported to be less sufficient compared to support in the 3 months prior to death (n=75; 49.3% ($\chi^2=14.79$, $df=1$, $p<0.01$)). Place of death did have some impact on respondents' views of quality of care. For home deaths, 78.9% (n=45) felt that they had received all the support that was needed compared to 59.3% (n=32) for hospital deaths ($\chi^2=5.06$, $df=1$, $p<0.05$). Forty eight (64.9%) reported sufficient support at the time of death for home deaths compared to 35.1% (n=27) for hospital deaths ($\chi^2=12.91$, $df=1$, $p<0.01$).

Table 3: Satisfaction with quality of care for deaths not described as sudden

Care location	VOICES questionnaire item	ID sample Frequency (%)	National sample Weighted %*
Home	Degree of help and support from health and social services (for deaths that were not described as sudden):		
	As much support as wanted	77 (63.1)	47.2
	Some support but not as much as wanted	28 (23.0)	21.0
	No although we tried to get more	7 (5.7)	16.4
	No but we didn't ask for more	3 (2.5)	14.7
	Not appropriate	36	
	missing	6	
	Were staff given enough help and support by the healthcare team at the actual time of death?		
	Yes, definitely	75 (49.3)	59.2
	Yes, to some extent	45 (31.0)	26.9
	No	25 (17.2)	13.9
	Don't know	6	
	Missing	6	
	Community nurse overall rating of care quality		
	Excellent	54 (60.0)	44.1
	Good	29 (32.2)	37.1
	Fair	3 (3.3)	12.6
	Poor	4 (4.4)	6.2
	Don't Know	1	
	N/A	41	
	missing	25	
	GP overall rating of care quality		
	Excellent	52 (44.1)	34.6
	Good	56 (47.5)	35.3
	Fair	7 (5.9)	17.5
	Poor	3 (2.5)	12.6
	Don't Know	1	
	Not appropriate	37	
	missing	1	
	Pain relieved at home		
	Completely, all of the time	38 (49.4)	17.9
	Completely, some of the time	23 (29.9)	31.3
	Partially	13 (1.3)	42.6
	Not at all	3 (4.0)	8.1
	Don't Know	9	
	N/A	64	
	Missing	7	
Hospital	Hospital pain relief		

	Completely, all of the time	28 (47.5)	38.6
	Completely, some of the time	22 (37.3)	29.8
	Partially	8 (15.6)	27.8
	Not at all	1 (1.7)	3.8
	Don't Know	13	
	N/A	84	
	Missing	1	
	Hospital doctors overall rating of care quality		
	Excellent	22 (28.6)	40.2
	Good	33 (42.9)	35.1
	Fair	17 (22.1)	15.3
	Poor	5 (6.5)	9.4
	Don't Know	4	
	N/A	73	
	Missing	3	
	Hospital nurses overall rating of care quality		
	Excellent	23 (29.5)	40.3
	Good	35 (44.9)	32.9
	Fair	16 (20.5)	15.7
	Poor	4 (5.1)	11.2
	Don't Know	3	
	N/A	73	
	missing	3	
All locations	All services rating of care quality		
	Outstanding	31 (20.3)	12.3
	Excellent	72 (47.1)	30.0
	Good	40 (26.1)	32.8
	Fair	5 (3.3)	14.8
	Poor	5 (3.3)	10.0
	missing	4	

*Frequencies not available for these questionnaire items

Comparisons with general population VOICES-SF data

The mortality profiles of the two samples were considerably different. Adults with ID died younger, from causes other than cancer or CVD, and their death was not as likely to have been preceded by a long illness. The ID sample were considerably younger than those in the general population sample, with just over a quarter (26.7%) over the age of 70 years compared to nearly 84% of the general population (Table 1). A higher proportion of the ID sample were reported to have died from causes other than CVD or cancer (64.8% compared to 41.4%). The level of deaths identified as 'sudden' was more than twice as high in the ID sample (17.3% compared to 8.2%) and considerably fewer were reported to have been ill for longer than one year before death (19.9% compared to 44.5%). The proportion who died at home was more than double in the ID sample (49.7% compared to 21.8%), although the ID sample only consisted of adults who had been living in an ID care setting at the time of death. The proportion who died in hospital was very similar between the samples, (49.7% compared to 46.8%). There were no hospice deaths in the ID sample compared to 6.5% of decedents in the general population.

There were differences between samples with regard to awareness of approaching death and care planning (Table 2), with the majority (61.5%) of the general population sample reported as knowing they were going to die ("Yes, certainly" or "Yes, probably") compared to only 21.8% of the ID sample. A much greater proportion of the general population sample were reported to have articulated a preference about where they wanted to die (34.9% compared to 12.4%). 86.3% of the general population decedents were reported to be involved in their care as much as they would have wanted, compared to only 45.8% in the ID sample.

Experiences of quality of care were generally rated more favourably in the ID sample than in the general population sample, but hospital care was generally regarded more favourably in the general population (Table 3).

Discussion

This study provides the first population-based account of the end of life care experiences of adults with ID in ID social care settings. Multimorbidity and challenging behaviour were very common, deaths occurred at a relatively young age and almost one fifth of deaths were regarded as more or less 'sudden'. Yet, despite these complexities, and perhaps contrary to what was expected, the quality of care at the end of life care was generally perceived as good, and the external support for care staff to provide care in the last three months reported acceptable. Adults with ID in these settings were no more likely to die in hospital than those in the general population. Our data also reveal that the proportion who accessed specialist palliative care nurses was similar in the ID and national samples. Additional data on availability or utilisation of services are required to explore access in greater depth.

Despite this positive picture, our data suggest that hospital services could improve their care for people with ID and their support workers at the time of death. Respondents in the ID sample rated community based care higher than hospital care, and were less positive about hospital care than those in the wider population. Hospital deaths were often associated with lower levels of support from external services prior to death. In addition, care workers felt less supported at the time of

death. Bereavement care is a fundamental component of quality end of life care yet the needs of care staff at this time are often overlooked²⁹ and the magnitude of the impact of death on ID care staff is often underestimated³⁰. Our findings suggest a need for interventions to better equip healthcare clinicians in all care settings to support ID care staff to look after their clients during the active dying phase. ID care settings are highly distinctive. They are small, community based settings where adults live, supported by non-nursing staff, for a considerable number of years. Those who work within them group negotiate a difficult and often invisible role, but may not, perhaps, meet the usual criteria of family or close friend. Initiatives developed in the non ID care home sector could be adapted for use and evaluated in ID social care settings³¹.

Individual involvement in decision-making and care planning is a further area for reform. End of life care preferences were only gathered in a small number of cases (far fewer than in the general population), suggesting that more emphasis could be placed on gathering patient priorities towards the end of life. Although numbers are small, those who did express a preference were more likely to die in 'the right place'. This link between gathering preferences and achieving preferences, has been demonstrated in the general population^{32, 33}. Awareness of approaching death plays an important role in involvement in care at end of life and we report that a very high proportion of deaths were sudden deaths. Although capacity issues and the high proportion of sudden deaths explain part of this, our findings raise important concerns that health and care staff may fail to keep adults with ID informed about their changing health status, as is sometimes the case in care for older adults³⁴. How conversations about health and prognosis are managed is an important area for improvement, and the issue of 'reasonable adjustments' under the Equality Act, 2010 and other equality legislation across the UK is pertinent. This is an issue for healthcare providers to lead as research suggests that giving social care staff responsibility for end of life care and death conversations within this population may not be successful³⁵.

There was a high proportion of unexpected deaths in the sample. Such deaths are more probable in an ID population⁴, and this still requires further investigation. We did not have access to death certificate data or medical notes so it was not possible for us to explore the nature of these deaths in detail. Potentially avoidable deaths are a cause for concern for those who look after adults with ID⁴. Research suggests that deaths 'amenable to healthcare', or otherwise treatable, are at least six times higher in the ID population²⁶. Whilst under-diagnosis has an influence, healthcare access difficulties, delayed diagnoses and poor illness management are thought to be involved^{8, 26}. Equally, the high proportion of unanticipated deaths in our sample may reflect communication barriers between people with ID, those who support them and healthcare staff, leaving carers ill-equipped to recognise deterioration and unaware that their client is approaching end of life. The barriers to timely end of life care interventions and how decisions are made about the need for end of life care represent important areas for future research.

Strengths and limitations

This study identified a sufficiently large number of deaths for analysis by recruiting service providers that supported over 12,000 adults with ID across the UK. Data were collected using a validated measure of end of life care and we report a higher response rate than other studies using VOICES^{24, 33, 36}. However, there are a number of limitations to our study. The first is that the sample excluded those living with families or other care settings. However, we needed to be able to select a population of adults with ID from which deaths could later be identified given the underreporting

of ID on death certificates ²⁶. We also only identified deaths where the decedent was still a client of the ID service. We are aware that some people may exit ID services and move to more generic longer term care for older adults (we are addressing this issue elsewhere), and experiences may be different in such settings ³⁷. Further research should explore end of life care for all people with ID regardless of their usual place of care. Our data on place and cause of death are reported, rather than extracted from death certificates but our data do not vary considerably from that reported elsewhere⁸ and error in death certification is a known problem^{38, 39}. Finally, the VOICES questionnaire was completed by paid care staff who may give a different account of care than bereaved family members or people with ID. This may have introduced recall and memory bias as well as bias arising from the nature of the relationship between care staff, decedent and service. However, research suggests that inter-rater reliability is good for questions about service use, as included in the VOICES questionnaire ⁴⁰ and it is only by using post-bereavement methods that data on circumstances surrounding the death can be collected ²⁵.

Conclusion

For the first time, we report on a population-based survey on end of life care for adults with ID. We note some positive experiences and highlight a number of areas for improvement. Health and social services seem to be enabling people with ID to stay in their usual residence at the end of their lives but may not have been offered enough support at the actual time of death or give sufficient encouragement to care providers to involve people with ID in care planning where there is capacity to do so. Since the population of people with ID is ageing (despite being markedly younger than the general population), multimorbidity associated with age and frailty means that their end of life care needs are likely to increase in complexity over time. Care facilities and their staff must be supported and equipped to provide the complex care that these people need as they approach the end of their lives.

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